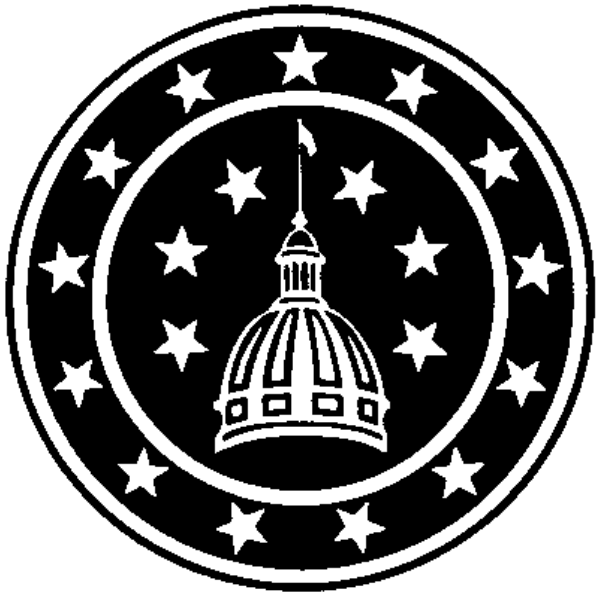
ANNUAL REPORT OF THE INDIANA COMMISSION ON MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES



Indiana Legislative Services Agency
200 W. Washington Street, Suite 301
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1999

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A copy of this report is available on the Internet. Reports, minutes, and notices are organized by committee. This report and other documents for this Commission can be accessed from the General Assembly Homepage at http://www.state.in.us/legislative/.

I. STATUTORY AND LEGISLATIVE COUNCIL DIRECTIVES

The Commission on Mental Retardation and Developmental Disabilities (MRDD) was established by P.L. 78-1994 to do the following: (1) develop a long-range plan for community- based services; and (2) review, make recommendations, and monitor changes regarding services to the mentally retarded and developmentally disabled population. P.L. 245-1997 amended the original legislation and extended the life of the Commission to January 1, 2001. P.L. 272-1999 amended the original legislation by extending the life of the Commission to January 1, 2005, and adding the following responsibilities: (1) reviewing and making recommendations regarding the implementation of the comprehensive plan prepared by the Developmental Disabilities Task Force (P.L. 245-1997, SEC. 1); and (2) reviewing and making recommendations regarding the development by the Division of Disability, Aging, and Rehabilitative Services of a statewide plan to address quality assurance in community based services.

The Legislative Council assigned the following additional responsibility to the Commission: study and monitor the services available to persons with developmental disabilities (HB 1543).

II. INTRODUCTION AND REASONS FOR STUDY

The creation of the MRDD Commission in P.L. 78-1994 was a response to the need for long-range planning and the determination of needs for people with disabilities. Two specific areas to be studied include the provision of residential services and the need for work-related services for persons with disabilities.

HB 1543-1999 proposed requiring the Division of Disability, Aging, and Rehabilitative Services within the Family and Social Services Administration to establish a program to monitor and assure quality in the delivery of services to persons with developmental disabilities.

III. SUMMARY OF WORK PROGRAM

The Commission met six times during the 1999 interim.

The first meeting of the Commission was held at the State House on July 21, 1999. Discussion topics at the meeting included: (1) organizational matters; (2) United States Department of Justice investigations of Muscatatuck State Developmental Center and Fort Wayne State Developmental Center; (3) quality assurance in the delivery of services to the developmentally disabled; and (4) the New Jersey Developmentally Disabled Offenders Program.

The second meeting of the Commission was held at the Muscatatuck State Developmental Center in Butlerville, Indiana, on August 17, 1999. Commission members were given a brief tour of the facility before the meeting. Testimony at the meeting addressed the following issues: (1) the release of Richard O'Brien as Acting Superintendent of Muscatatuck State Developmental Center; (2) the impact of the Department of Justice investigation on the operation of

Muscatatuck State Developmental Center; and (3) concerns of parents and other family members of Muscatatuck State Developmental Center residents.

The third meeting of the Commission was held at the Fort Wayne State Developmental Center in Fort Wayne, Indiana, on September 2, 1999. At the meeting held after Commission members completed a tour of the facility, the Commission heard testimony on the following: (1) the operation of Fort Wayne State Developmental Center; (2) the need for a comprehensive plan for providing long-term care, including attracting and training care givers; and (3) concerns of parents and other family members of Fort Wayne State Developmental Center residents and others with disabilities.

The fourth meeting of the Commission was held at the State House on September 28, 1999. The Commission heard testimony on the following: (1) the implementation of the 317 Task Force plan; and (2) group homes, including licensing, funding, and inspection.

The fifth meeting of the Commission was held at the State House on October 13, 1999. At this meeting, the Commission heard testimony regarding the New Jersey Developmentally Disabled Offenders Program and the need for the establishment of a similar program in Indiana. The Commission also directed the preparation of two preliminary drafts.

The sixth meeting of the Commission was held at the State House on October 26, 1999. Topics discussed at this meeting included: (1) the implementation of the 317 Task Force plan, including the participation of the Area Agencies on Aging; and (2) wage parity for direct care givers in community settings. The Commission also discussed preliminary draft legislation.

IV. SUMMARY OF TESTIMONY

317 Task Force Plan

P.L. 245-1997, SEC. 1 (i.e., SB 317-1997) created the Developmental Disabilities Task Force to prepare a written comprehensive plan of implementation for the future of community living arrangements for persons with mental retardation and developmental disabilities in Indiana. As part of its written plan (i.e., the "317 Task Force Plan"), the task force recommended the appropriation of $39 million over the 1999-2001 biennium to expand the services available. The 1999-2001 budget passed by the General Assembly included this appropriation.

Officials of the Family and Social Services Administration (FSSA) informed the Commission that the additional $39 million appropriated by the General Assembly in the 1999 legislative session is being used in a variety of ways, including reducing the waiting lists for various services, increasing the funding for respite care, and providing intervention in crisis situations. Since July 1, 1999, 127 persons with developmental disabilities have begun receiving services as a result of the appropriation. FSSA officials explained that funds used to transition persons from state developmental centers to community settings came from the general budget appropriation for the Division of Disability, Aging, and Rehabilitative Services (DDARS), not the $39 million.

Some Commission members and witnesses expressed concern over whether a portion of the recently appropriated funds would be reverted to the general fund instead of spent on providing services to eligible individuals; however, DDARS officials indicated their intention to spend all the money on services.

FSSA officials told the Commission that the agency has applied to the federal Health Care Financing Administration (HCFA) for permission to add a category to the Medicaid waiver to allow FSSA to provide services to persons on an emergency or priority placement basis. The new category, if approved, would add approximately 120 waiver slots. A ruling on the application is expected by mid-November.

Officials with the Area Agencies on Aging (AAA) explained to the Commission the role that the AAAs play in the implementation of the 317 Task Force Plan. AAAs serve as the single point of entry into Indiana's Medicaid waiver programs and also provide case management and other services to waiver recipients. The average time an individual spends on the Medicaid waiver waiting list after applying for services through an AAA and before a waiver slot becomes available is two to three years. Sixty days after notice of a waiver slot opening is the target date for services to begin.

The Commission declared that it is important for the Commission to continue oversight of the implementation of the 317 Task Force Plan, including the funds spent on administration of the program compared to the funds spent on providing services.

State Developmental Centers

Commission members toured the Muscatatuck and Fort Wayne State Developmental Centers. FSSA officials reported the results of 1998 investigations of the centers by the United States Department of Justice (DOJ) and changes that have been made by DDARS in response to issues identified in the investigations. The deficiencies identified in the DOJ report were as follows:

(1) Instances of misuse of restraining medications and physical restraints.
(2) Inadequate life skills and behavior skills training for residents and psychiatric services.
(3) Instances of residents inflicting injuries upon themselves or other residents.
(4) Instances of inadequate health care.
(5) Inadequate levels of integrating residents into community settings.

Testimony discussed the decertification of Muscatatuck State Developmental Center (MSDC) which resulted in the loss of federal Medicaid reimbursement for the center. DDARS officials expect MSDC to be recertified by the end of 1999 and plan to begin the search for a new superintendent for MSDC in the first quarter of 2000 to take over the operation of the center after the division's contract with Liberty Healthcare expires.

Public testimony discussed problems that have resulted after the DOJ investigations, including changes in patient medications and the discontinuance of certain restraint methods. Testimony also discussed the difficulties the centers often have in hiring and retaining sufficient staff. Factors identified as

contributing to these difficulties were low unemployment rates across the state, the difficult nature of the work, the lack of sufficient training, the low wages as compared to other jobs (e.g., fast food), and the bad publicity that is often given to the centers. Family members also expressed concern over the possible closing of the centers.

Group Homes

Testimony discussed the licensing and inspection of group homes. DDARS licenses only those group homes that receive Medicaid funding. There are currently 548 licensed group homes in Indiana. Licensed group homes are inspected annually by the Indiana State Department of Health (ISDH) through unannounced visits that last an average of two to four days. ISDH annual surveys reveal an average of one to two deficiencies per group home, with 45% of group homes found deficiency free. Recommending decertification for receipt of federal Medicaid money is ISDH's only remedy against a group home. ISDH has recommended decertification for three group homes in 1999, the only such recommendations made in five years. HCFA regulations govern the level of care required for an individual to reside in a group home. ISDH is responsible for citing violations of the level of care regulations, and DDARS is then responsible for finding a new placement for the individual involved.

Testimony discussed that group homes often face the same difficulties in hiring and retaining sufficient staff as do state developmental centers, with many of the same contributing factors (e.g., low unemployment, difficult work, lack of training, low wages). Services for individuals with dual diagnoses (i.e., both mental illness and mental retardation or developmental disability) were noted to be insufficient. The number of new group homes needed in Indiana, if any, is not identifiable. The cascading approach to group home waiting lists used by DDARS (i.e., moving out people who no longer need or want to live in a group home and moving in people from the waiting list) appears effective. An area of possible expansion is group homes for children. Suggestions were made regarding the possibility of converting empty buildings on state developmental center grounds into small group homes.

Officials from the Office of Medicaid Policy and Planning (OMPP) explained that services provided to persons in group homes through the Medicaid waiver must cost less than the cost of providing care to those persons in state developmental centers. This cost comparison is now made on a state-wide basis, not for each individual served.

Quality Assurance

DDARS officials presented information regarding the methods the division uses to monitor the quality of services delivered to individuals with developmental disabilities who are served through Medicaid waivers. These methods include the following:

- Provider certification.
- Provider monitoring.
- Case management.
- Follow along studies.
- Consumer feedback.
- Quality monitors.
- Critical incident reporting.

- Consumer protection and rights, including:
  - Adult protective services/Child protective services
  - Medicaid appeal rights.
  - Statewide developmental disabilities ombudsman.
  - Indiana Protection and Advocacy Services Agency.

Testimony also discussed the importance of tracking the progress of individuals who are moved from state developmental centers to community settings. FSSA officials presented information regarding the status of individuals who were moved out of Central State Hospital, New Castle State Developmental Center, and Northern Indiana State Developmental Center when the facilities were closed.

New Jersey Developmentally Disabled Offenders Program

Testimony related several situations regarding difficulties that have arisen when persons with developmental disabilities became involved in the criminal justice system. Issues that are often present when persons with developmental disabilities are charged with a crime include a developmentally disabled accused person's lack of understanding of the criminal justice process, false confessions due to a willingness of the accused to please those in authority, and a lack of training in identifying suspects who have developmental disabilities. New Jersey is one of the few states that have established a program to provide persons with developmental disabilities supports in the community while still holding them accountable for their criminal acts. The New Jersey program involves many sectors of the criminal justice system, including prosecutors, defense attorneys, probation and parole systems, and the human services system. Testimony discussed the need for further study into this area.

Wage Parity for Direct Care Givers in Community Settings

Testimony discussed the important role that direct care givers play in providing quality services to persons with mental retardation or developmental disabilities in community-based settings. It was noted that the wages paid to direct care givers in community-based settings have not increased in several years and are currently below the wages paid for similar jobs in state developmental centers and in other types of jobs (e.g., fast food).

The Commission declared that wage parity for community care givers is a critical issue that should be looked at in more detail next summer, with the possibility of drafting legislation for introduction in the 2001 budget session.

V. COMMITTEE FINDINGS AND RECOMMENDATIONS

At the October 26, 1999 meeting, the following findings and recommendations were made:

The Commission approved PD 3508 by a vote of 10 to 0. This preliminary draft requires supervised group living programs for the developmentally disabled (a/k/a "group homes") to post in a conspicuous location a toll free number for reporting complaints. This draft also requires the Division of Disability, Aging, and Rehabilitative Services and the State Department of Health to include on all

written materials given to residents of supervised group living programs and their families or legal guardians a toll free number for reporting complaints.

The Commission approved PD 3542 by a vote of 10 to 0. This preliminary draft requires the Department of Correction, in cooperation with the Office of the Secretary of Family and Social Services (i.e., FSSA), to conduct a study regarding persons with developmental disabilities who are incarcerated or otherwise involved with the criminal justice system and to present recommendations for components of a program to address those issues. The draft requires the results of the study be presented to the MRDD Commission by September 30, 2000.

W I T N E S S L I S T

Expert Testimony

• Charles C. Burch, Executive Director, Law Enforcement Training Board, Indiana Law Enforcement Academy
• Lynn Carson, Mental Health Association, Marion County
• Sheri Caveda, Chairperson, Long-Term Care Committee, Council of Volunteers & Organizations for Hoosiers with Disabilities
• Pat Cockrum, Chief Executive Officer, Sycamore Services, Hendricks County
• Gerald Coleman, Assistant Commissioner, Health Care Regulatory Services, Indiana State Department of Health
• Richard Dever, Professor Emeritus, Indiana University, Bloomington
• John Dickerson, Executive Director, The ARC of Indiana
• Kim Dodson, Director of Governmental Relations & Development, The ARC of Indiana
• Senator Beverly Gard, District 28
• Kathy Gifford, Assistant Secretary, Office of Medicaid Policy & Planning
• Representative Gloria Goeglein, District 84
• John Guingrich, Program Director, League for the Blind & Disabled (Fort Wayne)
• Sheriff Nick Gulling, Hancock County
• Marjorie Gurnik, Director, Policy and Budget, Family & Social Services Administration
• John Hill, Deputy Director, Division of Disability, Aging, & Rehabilitative Services
• Steve Hinkle, The ARC of Northeastern Indiana
• Matt Hopper, Legislative Liaison, Indiana State Department of Health
• Sue Hornstein, Director, Long Term Care, Indiana State Department of Health
• Wendell Hunt, Acting Superintendent, Muscatatuck State Developmental Center
• Costa Miller, Executive Director, Indiana Association of Rehabilitation Facilities

• Dr. Ajit Mukherjee, Superintendent, Fort Wayne State Developmental Center
• Lynn Nelson, Deputy Director of Aging & In-home Services, Area 4 Agency on Aging
• Lauren Polite, Legislative Liaison, Family & Social Services Administration
• Dr. Peter Sybinsky, Secretary of the Office of Family & Social Services
• Dawn Tyler, Director, Case Management, Area 2 Agency on Aging/Real Services
• Debra M. Simmons Wilson, Director, Division of Disability, Aging, & Rehabilitative Services

Family Members of Persons with Disabilities
Don Borem
Charlie Cox
Bob Egner
Frances Egner
Carolyn Ernstberger
Mary Harmon
Irene Homan
Gary Jackson
Barbara Jenkins
Frank Lori
Linda Martan
Carolyn Matczack
Bea Nicosin
Miriam Ogan
Fredus Peters
Arlene Scroggham
Mary Louise Wesselman